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ABSTRACT

This report describes an outreach program that provides service coordination and home-based early intervention for disabled infants and toddlers on the Navajo and Hopi reservations in Arizona. Developed by the Institute for Human Development (IHD), the outreach program uses paraprofessional instructional aides that are based in six northern Arizona reservation communities and speak the language of the communities they serve. IHD's paraprofessional model contains the following elements: (1) hiring and training local paraprofessional instructional aides who are familiar with the local culture, speak the local language, and are recognized and trusted; (2) identifying and evaluating children with disabilities within a 60-mile radius of the aide's home community, and forwarding referrals to the Division of Developmental Disabilities for confirmation of eligibility; (3) learning about specific resources in each community; and (4) encouraging local agencies to take over programs started by IHD and supporting new locally-administered programs with staff training and technical assistance. When a child is eligible for services, an Individualized Family Service Plan (IFSP) is developed that addresses the needs of both the child and the family. The annual IFSP is a team effort of parents, the paraprofessional aide, the IHD early intervention specialist, a case manager from the state agency, consulting therapists, and any others involved in the child's case. IHD also assists families with the transition from early intervention services to preschool programs. Advantages of this paraprofessional model are listed. (LP)

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EARLY INTERVENTION IN RURAL NORTHERN ARIZONA

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The professional literature on early intervention highlights the importance of early identification and treatment in reducing the impact of disability on children and families. The federal government recognized this and passed P.L. 99-457 in 1986, making money available to states for planning coordinated early intervention services.

P.L. 99-457 stipulates that early intervention services be family-centered; the focus is on the family as the primary support for a child's development. The law intends that the family of a young child with special needs receive services that maximize the child's strengths and facilitate his/her development.

The Institute for Human Development (IHD), a University Affiliated Program at Northern Arizona University in Flagstaff, has provided early intervention services in rural northern Arizona since the mid-1970's.

The IHD provides early intervention and related services for children birth to three years of age, and their families, who live in Flagstaff and on the Navajo and Hopi reservations. The IHD currently serves up to 50 children with disabilities or who are at risk for developmental delays. Delays in development range from mild to severe and may be related to factors such as prematurity, mental retardation, Fetal Alcohol Syndrome, or cerebral palsy. Services are family-oriented and usually provided in the home.

In Flagstaff, graduate students and the Early Intervention Coordinator provide service coordination and home-based early intervention for children. Services are provided in individual and small group settings.

This discussion focuses on the project's Outreach program on the Navajo and Hopi reservations. The Outreach program illustrates how a community-based service model can use local paraprofessional staff effectively.

Geographic and Cultural Considerations

The IHD Outreach model for early intervention developed over ten years, in response to the geographic, linguistic, and cultural characteristics of northern Arizona.

Flagstaff, Arizona (elev. 7,000 ft.) is a community of about 43,000, located at the base of the San Francisco Peaks. It is the major "metropolitan" area in northern Arizona. The geography of northern Arizona includes deserts and mountains, and the climate can be extreme. Snow, mud, and unpaved roads complicate service delivery to remote reservation communities. The IHD Early Intervention Project serves three counties encompassing 39,847 square miles, with a population of about six people per square mile.

Northern Arizona culture varies as much as its geography. Outreach Program paraprofessional Instructional Aides on the Hopi and Navajo reservations live in, and speak the language of, the communities they serve. Speaking a family's native language, the Instructional Aide helps the child learn skills more easily and helps parents understand concepts for which there are only English words.

Respect for the balance between traditional cultural practices and family participation in formal services is critical to the success of service programs in multicultural setting. For example, the family of a child with dislocated hips might choose to follow the advice and

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practice of a traditional medicine man rather than pursue Western medical intervention. Outreach Program professionals and Instructional Aides must reserve any personal influence and judgment and preserve the family's right to choose.

The IHD Early Intervention/Outreach Model

The IHD Outreach early intervention model evolved from University-based professionals' efforts to provide services to young children and families in rural northern Arizona communities. This city-based professional program was expensive, and contact with families was infrequent. Travel distances, inadequate telephone services, and cultural and language barriers hindered consistent, family-focused intervention.

Today, Instructional Aides are based in six very diverse northern Arizona reservation communities. The aides provide home-based intervention within a 60-mile radius from their own homes. Schedules are determined by the number of families assigned, the distance to each home and how often the children are seen. An Early Intervention Specialist from Flagstaff travels about 1500 miles each month visiting service sites.

Establishing Early Intervention Service Sites in Rural Reservation Communities

The IHD's paraprofessional model develops programs specific to the needs and available resources of each community, according to four steps:

1. Identify and evaluate children with disabilities within a 60-mile radius of a rural community. Identify children with significant delays through phone conversations with community health professionals, Head Start staff, school personnel, and Arizona State Division of Developmental Disabilities staff. Identify important Tribal agencies which should be informed and involved in the project. Visit the community to confirm the eligibility of children recommended for services. Forward referrals to the Division of Developmental Disabilities for confirmation of eligibility.

2. Hire and train local paraprofessional Instructional Aides who are familiar with local culture, speak the local language, and are recognized and trusted. Advertise Instructional Aide positions in newspapers, on bulletin boards at local trading posts, on local radio stations and through word of mouth. Screen written applications for educational background and experience with children (with or without disabilities). In interviews, assess applicants' abilities to work independently, to be innovative and flexible, and to communicate with co-workers and families.

   Instructional Aides are trained in topics which include: developmental checklists implementing Individualized Family Service Plan objectives; data collection; seizure management; philosophy and principles of developmental disabilities; family support; CPR; and first aid. Training is an on-going process including on-site monthly follow-up and supervision by an Early Intervention Specialist.

3. Learn and use the specific resources in each community; this is critical to the success of this program. Does the community have a hospital? Therapists? What transportation exists? For example, in one community, a private agency operates a van to pick people up at their homes and take them to medical appointments.

4. Enable local agencies to take over programs started by the IHD. The IHD initiates and develops services, with the goal of turning administrative responsibility over to community-based agencies. Remain available to support new locally-administered

programs with staff training and technical assistance. As communities become aware of young children's needs and local people are trained to provide quality services, the IHD and the state agency can shift funds to other rural areas in northern Arizona where young children need early intervention services.

IFSP and Program Planning

The Arizona Department of Economic Security/Division of Developmental Disabilities funds the Early Intervention Project and determines a child's eligibility for services. When a child is eligible for services, an Individualized Family Service Plan (IFSP) is developed.

The annual IFSP is a team effort of the children's parents, the Instructional Aide, the IHD Early Intervention Specialist, a Case Manager from the state agency, consulting therapists, and any other people involved in the child's treatment. Curricula such as the Carolina Curriculum for Handicapped Infants and Infants at Risk assess the child's most critical areas of delay.

A young child's needs are inseparable from the family's needs. The IFSP includes a Family Survey which lists common concerns of families with children having special needs. Parents can complete the Family Survey in writing or by interview, and are asked to set priorities for the child and the family.

The Aide has primary responsibility for teaching the child the skills identified in the IFSP. The Flagstaff Early Intervention Specialist visits each of the six service sites monthly and reviews the child's progress with the Aide, to determine if changes in teaching strategy are needed.

Progress toward meeting family needs identified by the IFSP is also closely monitored. Family needs change, as must the strategies for meeting them. Examples of family needs which might become IFSP goals are:

- In one community, the Instructional Aide worked with a women's shelter and Tribal social workers to serve a woman and her two children with disabilities. The woman was threatened with domestic violence and faced a possible divorce.

- In another community, the Aide worked with Navajo Housing Authority staff to get an apartment in town for a family from an area that was inaccessible in winter.

- A child needed medicine that required refrigeration. His family's hogan had no electricity, but did have a small propane tank for a gas stove. The aide succeeded in getting the state disability agency to pay for a propane refrigerator, and convinced the gas company to install a larger propane gas tank.

An annual parental consumer satisfaction survey helps the IHD plan changes in services.

Preschool Transition

P.L. 99-457 allows children as young as 3 years of age to receive public school special education services. Transition from early intervention services, which are usually home-based, to preschool programs, which are typically center-based, can be an exciting, yet worrisome time for a family and child.

The Instructional Aide and Early Intervention Specialist inform parents of the child's right to attend school at age three, and discuss options and provide legal information on preschool placement. The Early Intervention Specialist coordinates transition planning with local education agencies.

When the child is 2½ years old, he or she has a formal diagnostic assessment through the Indian Children's Program (ICP). The ICP Assessment Team is a rather unique local resource available through collaboration of the University Affiliated Programs in Arizona, New Mexico, and Utah. This team generates a comprehensive report providing a child's new school with valuable diagnostic information,

teaching strategies, and placement recommendations.

Conclusion

The advantages of this paraprofessional program model for early intervention services are:

1. The Instructional Aides are familiar with the culture, language and geography of their communities.

2. The combined knowledge and experience of the University-based professional Early Intervention Specialist and local paraprofessionals makes an effective team. The Instructional Aides are comfortable with and trusted by families; the Specialist is a professional resource with knowledge and experience of young children.

3. The program employs local people in communities where unemployment is high.

4. The program is cost-efficient. A comparable program using professional staff to serve 30 children living in remote areas would be much more expensive.

5. The paraprofessional program ensures consistent services to families who might otherwise receive limited or no services.

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